

How Do You Grieve During an Apocalypse?

by Jessie Male | Issue 11.2 (Fall 2022), Crip Pandemic Life: A Tapestry

ABSTRACT This essay is a rumination on loss during the pandemic—not only the physical loss of loved ones but the loss of experiences and time. Focusing specifically on the death of my aunt, Joyce Dana Apostole, I reflect on what it means to mourn, not only as an individual but as a collective. Through the retelling of significant moments in Joyce's life and recalling our relationship, I consider the questions: How do you navigate grief when you cannot congregate with others? How is that grief compounded by institutional failures—medical, governmental—and informational lack? And how does social response to individual and mass loss reflect philosophies and policies that (continue to) devalue—and prove detrimental to—the lives of disabled people? Ultimately, this essay is not only a reflection on grief, but it is also a eulogy, an opportunity to fully recognize my aunt and her complex history, a life shaped by illness and disability in ways that counter popular narratives of recovery and overcoming. It is an archive of not only what was, but what wasn't, necessary documentation within a culture in which "return to normalcy" can become synonymous with forgetting.

KEYWORDS [grief](#), [memory](#), [pandemic](#), [COVID-19](#), [memoir](#), [polio](#), [eulogy](#)

Start with a memory.

My Aunt Joyce sits on her bed cross-legged, family surrounding her as if she is royalty. We've come on one of the "bad days." Joyce's words jumbled in a dialect of pain or pain meds; we could never be sure. Doctors say it's dementia and that she doesn't understand what is happening, but I don't believe them. I watch as Joyce watches, following the turn of a spoon filled with oatmeal as it is directed into her mouth. "Just one more bite," her daughter insists, but Joyce refuses. She has a notorious sweet tooth and I imagine the bland oatmeal is unappealing. She looks over at me and sticks out her tongue while crossing her eyes, like she always did to make me laugh when I was a child. My cousin once again attempts to feed Joyce. *Enough enough*, Joyce mouths, as she tries to push the oatmeal away.

"I don't want to remember her this way," my cousin says. I don't respond. As a memoirist, I am not inclined towards erasure, frontloading joy, reconstructing reality. I look around the

room that I know intimately. It is the last time I am there, though I don't know it yet. It looks the same as it did when I was a child, the mauve walls and large wooden dresser covered in medication bottles and jewelry. How many holidays and birthdays had I observed myself in the oversized mirror, avoiding drunken family conversation and finding a moment of respite? The room is filled with stuffed animals, porcelain dolls, and angel figurines. A small TV hums in the background. I spot the curled tail of Joyce's eighteen-year-old cat, Raina, who is hiding. So many of my aunt's comforts in one small setting.

In the bed, Joyce leans against a "husband pillow," like the one I had in college, with a built-in koozie so I could study with a drink. She sways forward and back, tipping towards me. The pillow isn't enough—isn't nearly enough. She needs more security. I say they should bring in a hospital bed for her to lie in, though I know it isn't that easy. My cousin talks about missed phone calls and forgotten deadlines with Medicaid. She says she tried to order something sturdier on Amazon, but the holidays are coming up, and thus delays in shipping. She and a family friend are managing around-the-clock care, the friend living in the apartment and my cousin staying over during his break on Saturdays. I don't understand why there isn't a caseworker or part-time aide providing support, and yet of course I do. I too have a parent in pain, and I know the many ways the system fails disabled people. I've seen the exhaustion and frustration that can come from constantly needing to advocate.

Later, when Joyce is dead, my cousin says all she remembers are the final months. The transport back and forth from Joyce's apartment to the hospital for treatment of bedsores and dehydration. The final move from hospital to nursing home during the bitter cold of February. Joyce's cries upon realizing they weren't going back to her apartment, and she wouldn't be able to collect her belongings. The image of Joyce waking up in a vacant room without Raina against her side. The first cases of COVID, the closure of the nursing home to family. A nurse pressing a phone to my aunt's ear so she can scream to a daughter she isn't allowed to see.

"Why did you leave me?" my aunt cries into the phone. "Why did you leave me."

When I think of Joyce's body, the way she held space, I think of her hands. Her long, manicured fingernails, unchipped, perfected at the salon every week.

"The day I stop getting my nails done is the day I die," Joyce would say. They were always painted a lacquered ballet pink. I'd eye the smooth surface as she clasped our hands in an embrace. When we'd visit her at her apartment in the Bronx, she'd call to me, "*Bubbe, come here bubela,*" and gesture towards an empty seat at the kitchen table, and roll herself towards me. Joyce loved to hold hands, and she would gently rub her thumb against my skin as she spoke to me. I both craved these moments and found them unnerving. I was

more like my mother—Joyce's younger sister—who was less fond of touch, preferring brief hugs or "a kiss on the *keppie*."

My mother and Joyce were so different and yet as children were treated as twins, dressed in matching clothing and taking up the same hobbies. In 1953, the two contracted polio from a public pool in Chula Vista, California. Their family had recently relocated after my grandfather's New York City butchery business failed and he refused to declare bankruptcy. It was supposed to be a *better life*—the phrase he repeated throughout their move— and for several weeks California seemed a place of pure possibility. In photographs, the sisters, five and seven years old, wear capri pants and halter tops, posing amongst palm trees. The family moved into a split-level rental and waited for their furniture to arrive from Brooklyn. It was mid-August, and the days were long. A public pool was the only respite from the heat.

My mother felt the symptoms first. She woke up and couldn't catch her breath, couldn't move her arms or legs. Days later, Joyce sat down on the toilet and couldn't get up. After Joyce's diagnosis, the sisters lay next to each other in a locked polio ward for thirteen days.

I grew up hearing the stories about this time, when *before polio* became *after polio*, a particular grief. Life split in two, quickly cut as if by a sharp knife. My mother, seemingly recovered, walked out of the polio ward, returning to the split-level house, basking in the illusion of the *before* times. Joyce remained paralyzed from the waist down and was transferred to a rehabilitation facility. Before she came home, the family moved into a ranch house so she wouldn't have to navigate stairs. My grandfather preferred she use braces as it was easier to pass as nondisabled, but years later, after Joyce had children, she chose to utilize a wheelchair full time.

As a child—and even later—I never understood the strangeness people associated with Joyce's wheelchair. The novelty. Strangers would approach Joyce and ask how she had children and she'd respond, deadpan, "I pushed them out of my vagina." When they told her how lucky she was to have a man who loved her, she'd respond, "He is lucky to be with me." Her humor was a weapon, and she deployed it with ease. In most photographs she harbors one of two expressions; she's been caught mid-laugh, or there is a secret she is keeping.

When I was very young—the baby of the family, and clearly her favorite—she'd pull me onto her lap and we'd roll through her apartment, banging into doorways like a game of bumper cars. Attached to the arms of the wheelchair were hair ties that were popular in the 1990s, shaped like an infinity symbol with big rubber balls on the ends. I'd roll them around with the palm of my hand. The small details you remember. Now, as the nineties are back in fashion, I always look for those hair ties at the pharmacy.

Back then, Joyce gave my belly button a nickname. She called it Lucille.

"Where is Lucille? Where?" she'd ask me, and I'd run to her, lifting up my shirt. She'd poke at my round child belly protruding over the top of the elastic waistband of my OshKosh B'gosh jeans.

"There she is!" she'd proclaim, and I'd fall into her, giggling.

And what loss I felt, years later, when I sat in the same apartment and Joyce held my hand and asked, "What did we call your belly button?"

We sat there for a long time, the two of us, tossing names back and forth: Betsy? Carol? Phil? Finally, one of us said, "Lucille. It was Lucille." There was a long pause. We'd just finished our annual Christmas dinner, and in the background, I could hear my father putting paper plates and empty Chinese food containers into large plastic bags. I wondered what else I had forgotten.

"Lucille. Why in the world would I ever call it that?" Joyce asked, breaking the silence between us.

Joyce dies on March 25, 2020, the same day the New York governor shuts down all non-essential businesses. At a press conference, the New York City mayor announces: "Things will continue to get worse before they get better." He adds: "Lives are on the line."

When my cousin calls to tell me about Joyce, I let it go to voicemail. I teach writing at NYU, and in a few minutes, I have a meeting with other student advisors about the recent shift online. Institutional changes are only getting started and I already feel at capacity. In my inbox, emails are stacked one on top of the other with capitalized subject lines. Students can't get their belongings from their dorms and are worried about meeting deadlines. They can't make it to class because their computer is shared with a sibling. They tell me about parents and grandparents contracting COVID and thus needing to take on additional responsibilities. I give out my phone number to students, renegotiating boundaries. One student calls from California and as I talk to him, sirens scream endlessly outside my Brooklyn apartment building.

My cousin texts PLEASE CALL ME and immediately I know what is coming. I look at the clock. The meeting I am supposed to be at is starting in four minutes. I teach my first online synchronous class in two hours, and I am nervous about navigating new technology. I wish I could postpone reality, but I know that is an unfair luxury. When I call my cousin back the conversation is brief. With a fifteen-year age difference between us, we are not close, our shared interests limited to celebrity gossip and family. After I get off the phone, I cry and email my supervisor, explain the circumstances, and apologize for missing the meeting.

She responds: *I'm sorry to hear about your aunt. What a difficult time to lose a family member.*

Seventeen months later, I look back at that email and almost laugh.

What a difficult time.

What a difficult time.

Then, in New York City, there were 6,506 positive cases of COVID-19 and 71 fatalities.¹ Then, we took the word of those who said Joyce probably died of a bacterial infection, that after years of post-polio syndrome and other ailments, her body had grown too weak. Then, we turned on the television and listened to our governor, who started each morning briefing with a smile and an announcement of the date. Pointing to data as if it was a countdown clock on New Year's Eve. Now, we know about the cover-ups, the numbers underestimated, the causes of death smudged or erased.

I don't like to think of Joyce's final moments or her final days. If nurses came when she called out to them, or if they ignored her due to understaffing and seemingly more urgent needs. The irony of a polio survivor probably dying either directly or indirectly from another highly contagious virus is not lost on me. That she died alone in an empty room resembling where she lay in a polio ward is an echo that makes me curl into my chest with a visceral ache.

Throughout the pandemic, I've often thought of the young adult book *The Giver*, which was required school reading in the 1980s and 90s. In the book, the main character, Jonas, lives in a community of "Sameness," in which he—The Receiver—is the only member who can access feeling, color, or memory. Everyone in the community has a designated role to fulfill, and those who are "unfit" to contribute to society—underweight infants, the elderly—are killed after a ceremony known as "release." The book is marketed as dystopian but now it reads as real life. In the years since COVID emerged, the desire for normalcy—for productivity—has superseded care for vulnerable members of the community. There are so many elderly and disabled people dead because of COVID and related neglect: the grandparents of my students; disabled activists and artists whose work we study. In class we unpack the rhetoric used to explain their deaths, the ways that doctors and politicians validate "difficult choices." The language used to soften inequity.

When Omicron barrels through the country— New York City, an epicenter once again—I listen, mouth open (though how could I possibly be surprised) as the CDC director proclaims that seventy-five percent of those killed by the new variant "were unwell to begin with."

"This is very encouraging news," the interviewer says.

"Very encouraging news," the CDC director repeats.

Towards the end of *The Giver*, Jonas's mentor—The Giver—states, "The worst part of holding the memories is not the pain. It's the loneliness of it. Memories need to be shared."² After Joyce dies, I want to enact the kind of exchange The Giver describes but sharing seems impossible. We cannot coordinate a funeral, or sit *shiva* at my cousin's home, or have late night toasts yelling "remember *that* time, remember *that* time." We cannot eulogize my aunt, or even resurface old tensions and fight. My cousin is relieved to learn obituaries aren't required in New York State. It is one less thing to do; in a pandemic, every responsibility feels ten times its expected size. In retrospect, I should have offered to write one, or at least set up a memorial website. Yet I too was overwhelmed. I only left the house for midnight grocery runs, or late-night outings with my husband and dog when we'd walk down the middle of deserted Brooklyn streets, not another person in sight.

I wish we had an occasion to be together and share stories. Our immediate family is small, but Joyce was one of twelve first cousins, just from the maternal side. In another version of this story, they are available to fill in the many gaps in what I know of her life.

Joyce was an expert storyteller, known to add flourish and spin. Characters compressed and plots edited for time. "Let me make sure I'm telling you the truth," Joyce told me once, and though I appreciated the transparency, I would have equally enjoyed a lie. I could listen to her for hours. She always had a story: about a husband, a boyfriend, a lover, the super she kissed when he came to check on her radiator, the FedEx guy, the long-lost teenage love from a summer in the Catskills (they spoke of a future together, but his parents forbid him from marrying a disabled woman) who she found forty years later and then spoke to on the phone every night. When she left her first husband—another polio survivor she met at a support group coordinated by my grandfather—she started dating a man who worked at the local deli and had a side gig as a bookie. Richie was a large Italian man with a gruff voice from years of throat cancer and the many polyps that had been removed. He drove a big black Cadillac with a large front seat Joyce could easily be lifted into. When he brought home stacks of hundred-dollar bills, she stuffed them into pillowcases, just in case. Joyce told me once—though without these specific words—their relationship wasn't romantic but was rooted in interdependency. He helped raise her children and later, a grandchild. She took care of him when he had one stroke, and then another, and then when the cancer spread to his brain and other parts of his body.

When Richie died, Joyce took over the bookie business. Medicaid didn't cover her bills, and she needed the money. She lived in a large apartment building on top of a very tall hill and men would use the intercom to buzz and ask for Richie.

"Just leave the money in a paper bag downstairs," Joyce told them.

"Isn't it dangerous?" my mother asked Joyce.

"What's the worst thing that can happen?" Joyce replied. "If they come here to break my legs, I'll tell them someone beat them to it."

She subverted the system in ways I could never fathom, was resourceful in ways I could never be—didn't *have* to be. What some saw as a slippery nature, was actually her self-advocacy.

Joyce is my muse, as is my mother, their shared experience with polio, and its aftermath, a constant focus of my writing. Yet this does not mean that Joyce is "an inspiration" or a narrative of recovery, the culturally idealized shift from suffering to normalcy. She took what she thought she was owed, once asking my mother to bail her out of jail when caught shoplifting (handcuffed to the door of the police car, she turned to the arresting officer and asked, "What do you think I'm going to do, run away?"). She was impulsive and temperamental, a combination meaning she and my mother would fight and go months or even years without speaking. And yet, some of the only times I've seen my mother laugh was when she was with Joyce. In a photograph, four of us sit on a white couch—Joyce, my mother, my older sister, and me. It's an impromptu photograph, caught at the end of a punchline. I'm no more than ten and laughing full-bodied, leaning forward with an open mouth and closed eyes. My mother is smiling, dressed in her L.L.Bean best, and Joyce is next to her in a bright blue tracksuit and sunglasses, though we're inside. She looks mid-dance, hands extended, and head tipped back. What was the joke? I want to press the picture like I do on my phone and watch a few seconds live.

Joyce was always a performer, as a young child the best in her ballet class, mastering leg and arm extensions while my far less enthusiastic mother was forced into tap dancing. After polio, Joyce stopped dancing and my mother began ballet. I've often thought of how Joyce felt, in the audience, watching her sister *jeté* and *pirouette* across the stage. Did she wish over and over it was she who danced and my mother who watched her? It all seemed so arbitrary, the different ways they recovered. It so easily could have gone the other way.

"There are so many ways that life can break your heart," the memoirist Grace Talusan writes.³ I've taught her book *The Body Papers* for several semesters in a class on disability memoir and return to that line each time. I think about this in relation to the initial fissure when the sisters got sick. As Joyce became older there were many other *befores* and *afters*. Before her boyfriend's parents forbade them from marrying. Before abuse by those in medical and educational settings (she described the crushed feeling of being pressed up against the wall by a high school teacher; the *squeak* of her crutches against linoleum as

she tried to run away). Before my grandfather's heart attack when Joyce was only twenty-five. Before my grandmother's diagnosis of dementia soon after. Before her first husband's drinking cost him his job and most of their money. Before Richie died. Before the post-polio syndrome caused her to feel like "I have polio all over again," as she described to me, weakening her arm strength until she could not transfer herself from bed to wheelchair, and revealing nerve damage that caused shooting pain down her back and legs.

She suffered, and that suffering is an important part of her story. Being a disability studies scholar I worry about that admission. As many in the field note, such a statement can be easily mobilized towards practices aligned with eugenic philosophies. Tobin Siebers warns that pain is used "as a motive force to justify disability oppression,"⁴ an actuality we witnessed early in the pandemic, when limited resources—oxygen, ventilators—meant nondisabled people were prioritized because of their assumed better quality of life. "She's no longer suffering," my cousin says when she tells me about Joyce's death. Her language of grief, the stories we tell ourselves. But my language is different. I know that Joyce suffered. I still want her to be alive.

One of the last times I saw Joyce, she gave me a bottle of hair conditioner. With Joyce, gifts were unpredictable. A handmade scarf. Bubble bath. Shoplifted earrings from Macy's or rings purchased from QVC. They often weren't my style, but I didn't mind. As the years passed, Joyce left the apartment less and less, and I am (as my husband will attest) a difficult person for whom to go shopping. Besides, I was no longer the baby of the family, and when we gathered for holidays, Joyce's grandchildren were the focus. They surrounded her, holding her hands, thanking her for their Barbie dolls and coloring books. A *Rock and Roll Christmas* in the background, they danced with her in the living room, wrapping paper and plastic boxes strewn at their feet. That visit, Joyce and I had a quiet moment, alone. She asked me if I was happy—she worried, knowing our family history of depression and anxiety. She asked me about children. I was thirty-six, four years married and finishing graduate school. The question of whether I would have a child seemed to be on everyone's mind.

"I don't feel ready," I told her. She was always a person to whom I could easily confess, to whom as a teenager I spoke freely about boys and intimacy.

"You don't need to rush it," Joyce said. "You still have time to decide."

It was so simple. It was nonjudgmental. She didn't try to convince me of one choice or another. What she said was just right.

The hair conditioner was useful. When I came home, I realized I had run out, and I placed the tall black and purple bottle prominently on the top shelf in my shower. I'd squirt the

conditioner into my hand, massage my scalp, and run my fingers through thick strands. My hair is long and dense, just like hers when she was younger, before she cut it pageboy length. Joyce would often talk about the similarities between us—our thick hair, our ample chests, our sensitive natures. I too was prone to outbursts. Our temperaments aligned. For more than two years, the conditioner has stayed on that shelf, compressed tightly between full bottles, flipped upside down, taking up precious space. I often think about putting it in the garbage, but not today. Maybe tomorrow. Not quite.

My grief is an empty bottle of conditioner.

My sister and I go to my cousin's house in Stamford, Connecticut. It's September 2020; almost Joyce's birthday. This is the first time since COVID that we've seen each other in person, though the three of us talk often on FaceTime. It's still months before any of us are vaccinated, and at first, we're not sure about hugging. When I finally wrap my arms around my cousin, I am struck by her skeletal frame, so narrow, like my mother's, who since Joyce's death has stopped eating and sleeps for fourteen or more hours at a time.

"Want to see my mom?" my cousin asks. I gasp, momentarily forgetting. In that second it can be 1987. It can be January 2020. My cousin takes us into the living room, and on the top of a cabinet a giant bronze urn is on display. Pictures of Joyce's grandchildren surround it. There is a large purple crystal in the corner. Small angel figurines. We have a moment of silence, and I tell my cousin it is a beautiful place to rest in peace.

We all have our idols, our small altars, our mementos. "Too many *tchotchkes*," my mother says when she enters my apartment. I admit—I attach objects to memories. Soon after stores reopen in New York City, I go to a Salvation Army. I roam the aisles, masked and touching fabrics, enjoying a moment without a television displaying the death rate. I spot a small plastic sculpture of a cat climbing out of a trunk and draped in white beads. Crudely painted dollar bills and coins line the base. JEWELRY, it boldly says on the front. It's ugly and impractical and of course I buy it; it features all of Joyce's favorite things. I place it on my writing desk, right below a framed picture of her at sixteen. The photo was taken at a talent show at the Catskills. In the picture, Joyce stands, relying on a brace to hold her weight. She's in a pale blue dress with a large pink belt cinched around her small waist. She's caught mid-note, long fingers extended, and mouth slightly open, singing alone on a stage.

My writing mentor, Louise DeSalvo, once told my graduate school cohort that we must write into our shame. What were we most scared to share with others? What would it mean to set that free?

I'm ashamed to admit that I don't think about Joyce much anymore, at least not in the day to day. When she was alive, we only saw each other two or three times a year, and especially as I became older, we spoke inconsistently. I know she wished our relationship maintained the ease of when I was a child, when we would swap Keds sneakers because we had the same size feet. Once, in my twenties, I went alone and visited her in her Bronx apartment and brought bagels and cream cheese for her and her aide. The three of us sat in her bedroom while she told stories about her childhood. She held my hand as she talked to me. I was grateful for the luxury of these hours together, without the distraction of other members of our family. "Come back anytime," she told me before I left. "It's so rare that I have company."

Why didn't I ever return by myself to talk with her further? During that visit, she was already in her sixties. Was I in such denial, so avoidant of the reality of her death, though she often spoke about its inevitability?

Admittedly, the weight of the past few years has made it more difficult to access many concrete memories of my time with Joyce. The space for grief and recollection has been compressed even further as COVID resurges. As I write this, during what I hope is the peak of the Omicron variant, there are over a million new cases reported each day. On the map of global hotspots, the United States is the color of coagulated blood. My husband and I meet friends for a walk in Prospect Park and air hug awkwardly when we say goodbye. At the grocery store I accidentally touch a woman's hand as we're both reaching for hummus, and I see the fear as she quickly pulls away.

But what I think about often—especially in the most isolated moments, of which there are many—is the *feeling* of being with Joyce. The anticipation as we took the elevator to her apartment. She was only on the second floor, and as the elevator crept up, I could hear her laughter, music on the radio, the ringing of the telephone as my father told her he found parking. Every step seemed choreographed, part of my favorite routine. Other than weddings or other large celebrations, we only saw each other at my childhood home or Joyce's apartment, and perhaps part of that comfort was in being so contained. When I close my eyes, I can see her opening the door to greet us, the rounded archways, the pink walls, the framed photographs adorning the hallway.

This is what I hold onto, the small scenes, the brief sketches. There is so much regret about what I have forgotten, memories pushed out to make more space. But how easily I recall the tight script of Joyce's writing on the cards she sent for every occasion, the curve of the "J" in both our names. How she patted the side of her bed for me to come close. The way she sighed before the most difficult part of a story. The sound of her voice on a message I forget to return, saying *I love you, please call me.*

Notes

1. "New York City, New York Covid Case and Exposure Risk Tracker," *The New York Times*, January 27, 2021, <https://www.nytimes.com/interactive/2021/us/new-york-city-new-york-covid-cases.html>. ↩
 2. Lois Lowry. *The Giver* (New York: Houghton Mifflin, 1993), 193. ↩
 3. Grace Talusan, *The Body Papers: A Memoir* (Brooklyn, NY: Restless Books, 2019), 130. ↩
 4. Tobin Siebers, "In the Name of Pain," in *Against Health: How Health Became the New Morality*, ed. Jonathan M. Metzl and Anna Kirkland (New York: NYU Press, 2010), 184, www.jstor.org/stable/j.ctt9qg6sk.17 < <http://www.jstor.org/stable/j.ctt9qg6sk.17>> . ↩
-

Author Information



Jessie Male

Jessie Male is the Postdoctoral Associate in Disability Studies at the University of Pittsburgh. She has a PhD in English from Ohio State and an MFA in Memoir from Hunter College. Her scholarly and interdisciplinary work appears in *Palaver Journal*, *Constellations*, and *Assay: A Journal of Nonfiction Writing*, among many other print and online publications. As an educator, she's developed disability studies curricula for face-to-face courses and online platforms, and she's been featured in *Inside Higher Ed* for her work in this area.

[View all of Jessie Male's articles.](#)

Article details

Jessie Male, "How Do You Grieve During an Apocalypse?," *Lateral* 11.2 (2022).

<https://doi.org/10.25158/L11.2.12>

This article is licensed under a [Creative Commons Attribution-NonCommercial 4.0 International License](#). Copyright is retained by authors.

Lateral is the peer-reviewed, open access journal of the [Cultural Studies Association](#).

ISSN 2469-4053

